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EXTRACT | 'Living and loving in the age of AIDS' by Derek Frost

news24 Derek Frost

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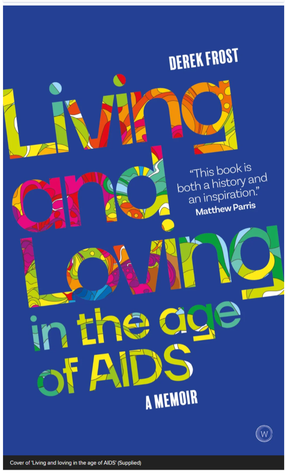

Cover of 'Living and loving in the age of AIDS' (Supplied)

Derek Frost, a distinguished designer, and J, a pioneering entrepreneur and creator of Heaven, the iconic gay dance club, met and fell in love more than 40 years ago. In the early 1980s it was discovered that J was HIV positive. In his book 'Living and loving in the age of AIDS', Derek Frost Derek describes a transformation of the spirit, how compassion and empathy rose phoenix-like from the flames of sickness and death, and how he and J founded the charity AIDS Ark, which helped to save more than 1 000 lives.

In April 2002, two days before my fiftieth birthday, J and I fly to Cape Town. Reaching 50 is an important milestone in every life. Starting Aids Ark seems to me an appropriate way to mark the event. Our objective is to find doctors with Positive patients who are dying for want of ART; to fund their treatment directly through these doctors and help save their lives. Aids Ark, it seems, will be alone in funding for this specific purpose at a time when others still choose to offer only palliative care.

Since our last visit to the country, a decade ago, there have been seismic changes. Apartheid has ended. Free elections have been held and the African National Congress are in power. By now four million South Africans are Positive, most of whom will die.

Andrew lived in London during the 80s. He remains a close friend. During that period we fought side by side in the same war. Now he lives in Cape Town where he, along with many others, has become increasingly horrified by the exploding numbers now dying of AIDS and that country's seemingly deliberate policy of misinformation and denial which can only be speeding this explosion. Andrew shares our ambition to "make a difference" and over subsequent years will prove tireless in helping Aids Ark flourish and grow. Through his introductions, we meet doctors and NGOs serving people living with HIV/AIDS. Amongst these are Professor Robin Wood and his equally eminent wife, Professor Linda-Gail Bekker. Both will become important in the fight to prevent deaths from AIDS. In South Africa through the initiative they founded – the Desmond Tutu HIV Foundation – and worldwide, with Linda-Gail becoming president of the International Aids Society.

We are shocked to discover how many South Africans believe that ARVs are ineffective and a Western poison designed to harm Africans. Many prefer to believe in the efficacy of traditional African medicine. The Sangomas, the so-called witch doctors, do not wish to see their status and power reduced by Western medicine and teach those who come to them for treatment to distrust ART.

We quickly learn that different cultures operate by different truths and rules.

In South Africa, some people think that having sex with a virgin cures HIV/AIDS. It's a myth that is perpetuated by traditional healers, who advise Positive men that having sex with virgin girls, even babies, will drive out the HIV virus. There has been a staggering rise in the number of child and infant rapes in the country, which UNICEF attributes to the "virgin cleansing myth".

We hear about a programme, taught widely in schools, which advocates chastity and teaches that practising safe sex provides no protection from HIV infection; that condoms provide no barrier and allow free passage of the virus like "a beetle through a doorway".

Rose Smuts, CEO of the Caring Network, tells us: "We might be able to persuade some of our Positive carers to take ARVs." If professional carers and nurses aren't convinced, clearly their patients won't be either. We're perplexed, we remind ourselves of J's attitude to these same drugs less than a decade ago.

Rose introduces us to Cobus du Plessis, an Afrikaner who works for a large Christian NGO and who is responsible for allocating their funds for HIV/AIDS care. Cobus is Positive and his health is not good. He shares the distrust of ARVs current in much of Africa and is speeding his own death by choosing not to take ART. Worse, by denying funding, he prevents access to these drugs to the thousands under his care. This makes me angry and I tell him so in no uncertain fashion. He cites as a reason the debilitating side-effects, to which I reply: "Cobus, the side effect of not taking ARVs is death. Which side effect do you and your beneficiaries prefer?"

We meet Nonkosi, a young lady in her early thirties. She is frail, thin and clearly desperately ill. Nonkosi had the courage to tell the congregation in her local church that she is Positive and has AIDS. Such bravery is rare when others have been killed, some by stoning, for making such a declaration. Much stigma is directed against those who are Positive. J is able to tell her that he has been Positive for over ten years and that due to taking ARVs is healthy again. Her initial disbelief transforms before our eyes into the knowledge and the immeasurable joy that healthy life may again become hers. Nonkosi will later become one of our early Aids Ark beneficiaries and our original poster girl. She agrees to us demonstrating the amazing effectiveness of ART, by showing an image of her formerly ravaged body beside a second picture taken one year later, showing her as a young woman whose fuller form, clear skin and shining eyes reflects her restored health. The text that accompanies our poster states: "Nonkosi after one year on ARVs."

At a Catholic run orphanage, we are introduced to 12 orphans who are Positive. They sit in a line along a shaded wall. Evidence of their varying Opportunistic Infections are clear to see. They are a silent, sad group. I wonder when each child was last taken into adult arms and hugged. He tell the nun who runs the centre that we currently have sufficient funds to purchase ARVs for only four of this group and they respond: "If you can't help all our children then we prefer to help none." We are saddened and confused by their response. Surely the survival of four is better than the survival of none? We tell them that additional funds may soon become available to help the remaining eight, but this nun still says no.

We are introduced to doctors of a Western persuasion and training who do understand that ARVs save lives. They are excited by our offer to fund ART. One doctor is so overwhelmed that he breaks down in tears. These doctors are suffering. It's hard for them, knowing that the medication is available, having no funds to buy it, and watching their patients die. Other doctors once fought to save J's life and the lives of our friends when they also had no drugs with which to save lives; when their patients also died. We feel the pain and the frustration of these South African doctors.

Due to their greatly reduced cost, we have decided to fund only World Health Organization (WHO) approved generic ARVs, but learn they are not licensed for use by South Africa's Medicines Control Council. We look elsewhere and source a supply from a pharmacy in neighbouring Swaziland where these drugs are licensed and the sale of generics cannot be prosecuted. The pharmacist tells us they are already sending drugs direct to South African doctors in the post; that the South African authorities seem unaware of, or choose to ignore, this fact. J and I make a personal commitment to provide "seed funding" for 20 beneficiaries.

We leave South Africa confident we have found suitable doctors to work with and have sourced a secure supply of WHO-approved generic ARVs. Our limited funding is in place and we are ready to receive our first applications for help.

- That was an extract from 'Living and loving in the age of Aids' written by Derek Frost and published by Watkins Publishing.

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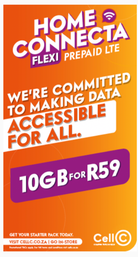

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